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ABSTRACT

The Fetal Alcohol Syndrome Project of the Indian Health Service was designed to identify existing cases of Fetal Alcohol Syndrome among the American Indian tribes (Navajo, Apache, Ute and 19 Pueblo Tribes) in the Southwest, establish a referral system to identify these children for treatment, estimate the prevalence of the problem, and work towards prevention of future cases. The project began in January 1980 by training clinicians, outreach workers, and community persons to recognize Fetal Alcohol Syndrome and milder alcohol damage for accurate referral, and to counsel and advise clients for the prevention of Fetal Alcohol Syndrome. In March, 1980, the clinical aspect of the project began and was established in communities where Fetal Alcohol Syndrome children existed. From the inception of the project to October 15, 1981, a total of 208 training sessions were held, 9,556 people were trained, 20 clinics were held in 15 locations and an average of 9.8 children were seen per day. A breakdown of diagnoses indicated that 30.2% of 205 children seen in clinics were Fetal Alcohol Syndrome, 15.6% were a milder degree of damage (Fetal Alcohol Effect), 6.8% were "suspicious" of pre-natal alcohol damage, and 47.4% were normal or had another type of birth defect. (ERB)

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# REPORT ON OUTREACH EFFORTS AND ANALYSIS OF APPROACH

October 16, 1981

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## A PILOT PROJECT ON FETAL ALCOHOL SYNDROME FOR AMERICAN INDIANS

Fetal Alcohol Syndrome is a pattern of malformations which is found in children born to mothers who drink alcohol excessively during pregnancy. The most common features of this syndrome include: various degrees of mental retardation, small size in birth length and weight, microcephaly, hypoplastic midface, growth deficiency throughout life, various joint abnormalities, a high frequency of cardiac defects, and hyperactivity (Jones, et.al., 1973; Streissguth, et.al. 1980). Of more recent concern is that moderate, mild and/or binge drinking may cause mild or less obvious forms of developmental damage. For this reason one can conceptualize the teratogenic effect of alcohol as a spectrum (Eckhardt, et.al., 1981). That is, while heavy drinking may result in Fetal Alcohol Syndrome, lower levels of consumption may result in mild growth delay, mild lowering of learning potential and other subtle defects. Currently Fetal Alcohol Syndrome is believed to be the second most frequent birth defect in the U.S. and the number one cause of mental retardation.

Since its first recognition and diagnosis in 1972-73, Fetal Alcohol Syndrome has been the subject of several hundred clinical articles dealing with both humans and animals. Articles describing programs designed to deal with the problem of Fetal Alcohol Syndrome, however have been few. Of specific interest in this paper, is a program designed to: identify existing cases of Fetal Alcohol Syndrome, refer these children to treatment, estimate the prevalence of the problem and work towards prevention of future cases.

The vast majority of literature on Fetal Alcohol Syndrome deals with the specific clinical manifestations of heavy maternal alcohol consumption on human and animal offspring (see Streissguth, et.al., 1980; Eckhardt, et. al., 1981). Of the few articles dealing with practical, applied interventions for the prevention of ethanol-induced birth defects, the approach is seldom programmatic. Some articles have been written on screening for alcohol-related problems in prenatal interviews (Sokol and Miller, 1980; Russel and Bigler, 1979). Other articles have been written on how patterns of alcohol abuse actually change in pregnant women (Little, et.al., 1976; Streissguth, et.al., 1977; Hook, 1978; Fried, et.al., 1980). Both of these types of articles have identified the need for, and have very generally described, community education to make women aware of the risk factor which alcohol presents to unborn babies (Sokol and Miller, 1980;

Carrigan, 1978; Little, et.al., 1980). The current literature on the incidence and prevalence of Fetal Alcohol Syndrome is also very scarce. At present, estimates of incidence exist for only the United States (Streissguth, et.al., 1980) Sweden (Olegard, et.al., 1979) and France (Dehaene, 1977).

Thus, as the clinical aspects of prenatal alcohol damage are becoming better defined, many other aspects remain unanswered. Programs which systematically address broader, non-clinical aspects of Fetal Alcohol Syndrome are not only rare, but virtually unreported in the literature. Described below, in detail, is the Fetal Alcohol Syndrome Project of the Indian Health Service. Because of the nature of the population and area served, it was designed to deal with a variety of unanswered questions regarding F.A.S., including its prevalence, treatment and prevention.

PROJECT INITIATION AND GOALS

The Fetal Alcohol Syndrome Project of the Indian Health Service was conceived and established as a special project for the International Year of the Child. The Indian Children's Program of the Mental Health Branch of the Indian Health Service (IHS ) convened a select committee of experts from various programs within IHS and it was decided to have a special initiative on Fetal Alcohol Syndrome. The experts from pediatrics, psychiatry, field clinics and other interests felt that Fetal Alcohol Syndrome was becoming a problem among some Indian tribes, but the exact nature and extent were unknown. Therefore a multifaceted plan was conceived which would approach it from a number of perspectives and answer a number of questions about Fetal Alcohol Syndrome.

As defined, the project was to accomplish a variety of objectives. Basically, training, treatment, and research were to be addressed. (See figure 1).

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Figure 1 about here

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Training was conceived as accomplishing two purposes: recognition and prevention. The training of clinicians and outreach workers was designed to aid in the referral of suspect children for diagnosis and treatment. Clinicians were trained in the recognition of Fetal Alcohol Syndrome and milder alcohol damage for accurate referral. Secondly, the clinicians and outreach workers could also use their knowledge in counseling and advising for prevention efforts with their clients. The major hopes for prevention, however, were believed to be in the community training sessions. Since Fetal Alcohol Syndrome is a totally preventable

birth defect, knowledge dissemination to the community people of all ages was considered to be vital. If people can be made aware that alcohol is a teratogen,* then primary prevention is possible. Women who do not drink while pregnant do not bear babies with Fetal Alcohol Syndrome.

The clinical aspect of the project was designed to accomplish several tasks. First, the committee who established the project knew that F.A.S. children existed among some Indian groups, but as a pilot project it was important to find out and document if Fetal Alcohol Syndrome children in the Indian population of the Southwest were clinically different than children reported in the general literature. Essentially, were the clinical manifestations of F.A.S. different in the service population and if so in what ways? Second, the treatment of F.A.S. children was and is an area where little information exists and therefore is of great need. Once children were diagnosed, a treatment plan was to be formulated for the child which would serve as a guide to coordinate all treatment and rehabilitation efforts for that child. The goal of the the treatment plan is to maximize the development of the child to his or her fullest potential, even though all of these children have limited developmental potential. Third, once the treatment plan was formulated, the referral of the child was to be made to the parent organization of the project, the Indian Children's Program. Care and treatment was then to be provided by a multidisciplinary team of specialists who would work with the specific problems and symptoms of the child for both specific and, eventually, overall habilitation. Finally, the clinics were conceived as an ideal opportunity for work with the mothers who have produced these children. Ideally the mothers would attend the clinics with their children, and could then be sensitively counseled regarding future pregnancies.

The research portion of the project was designed to greatly expand the overall knowledge base about Fetal Alcohol Syndrome among Indians. From the above material one can see that the training and treatment efforts were designed not only as services to the population, but were essential to the research effort. Specific data were to be kept on all children and this would provide insight for the many research questions. Specific research goals were: establishing incidence

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*A substance which impedes or damages the development of unborn babies.

and prevalence figures for the service population and sub-populations (individual tribes); gathering knowledge relevant to etiological (causation) factors or factors related to Fetal Alcohol Syndrome in the population; and utilizing this knowledge for devising prevention strategies.

Thus, even though the goals of the program were broad and seemingly diverse, the different activities were designed to complement one another. The training is to make people of all types aware of the problem and to allow them to recognize these children. This is important not only for prevention, but also to provide referrals for diagnosis and treatment. Clinics held for these children and other follow-up treatment in turn, provide the opportunity to learn from these children for their benefit, but also to provide data for the research effort. In general, then, the project was set up as a systematic and comprehensive approach to the problem.

## THE REFERRAL SYSTEM

The referral system established to accomplish the goals has been critical to the project. As can be seen in figure two, a suggested pattern or chain of referrals was set up which included a path from the local community to the treatment of the child.

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Figure 2 about here

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Identification of the children with problems is initially made in the local communities, clinics and hospitals. Referral then is to flow to the "designated persons" at each clinic or hospital. The designated persons are one to four professionals at every hospital or clinic who are: particularly interested in F.A.S.; who have been trained through lecture and clinic exposure with a consultant dysmorphologist from the project; and who make tentative diagnoses on F.A.S. and refer suspects to the project. Designated persons are generally physicians (pediatricians or general medical officers) or nurses (clinic supervisors or public health nurses) who work closely with the F.A.S. project to set up clinics and to insure referrals and clinic attendance. When clinics are set up they are held in the local service unit (hospital or clinic). A consultant dysmorphologist and one or more representatives from the F.A.S. Project are brought in and after chart review, discussion and ½ to 1 hour with the patient, a final diagnosis is

made and a specific treatment plan is finalized. When the treatment plan is typed, copies are transmitted by the F.A.S. Project through the designated person to the child's chart at the local service unit, kept by the F.A.S. Project, and presented to the Indian Children's Program and other appropriate treatment agencies and personnel. The treatment and evaluation is to be done and coordinated by the Indian Children's Program in a multidisciplinary manner. The multidisciplinary team is to coordinate and provide the needed services to the child, refer the child to appropriate sources if they are not available within the team and to teach local people (both lay and professional) special techniques which are needed by the child. All treatment is optimally carried out in the local community at all times.

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Figure 3 about here

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In the entire referral system, cooperation and coordination is important. Many different people are needed to make the system work. From initial referral to follow-up, cooperation of various types of professionals and laymen is vital. In all stages of the process it is imperative that some flexibility and variability be allowed in the referral system so that the particular needs, conditions and circumstances of the local clinics personalities, etc, are taken into consideration. Project needs have to be met in a manner which is unobtrusive for the local clinic. Also it has been vital that the F.A.S. project serve as the ultimate coordinator and assumes ultimate responsibility for the children.

Of particular advantage to the project has been the sharing of all types of F.A.S. information (research and aggregate level) with all participants in the referral system. New knowledge and unique findings from both the project and from literature written in other parts of the world have been used as motivation factors in the entire project. The fact that this syndrome was only recently recognized adds vitality, freshness and discovery to the other motivating factors of human service and medicine.

STAFF

The staff of the F.A.S. project consists of four regular personnel and two consultants. The specific breakdown is as follows: ½ time Director, (Ph.D.), two full time Field Coordinators, (B.S. and A.A.), full time Secretary,

and two consultant Dysmorphologists (M.D.). All of the staff has extensive experience in Indian health care and on the local Indian reservations. Two of the staff are Indians from the local area. Extensive coordination with a variety of agencies is a vital part of the project. Only through extensive knowledge of both the Indian Health Service and local, tribal systems and through team work is the project possible.

The director is responsible for overseeing all aspects of the project from training and research to relationships with agencies, tribes and administrative matters. Specific skills needed by the director are professional training in epidemiology, field research, and community health and an intimate knowledge of the tribes and resources of the work area. The director performs a considerable amount of training of a variety of individuals from physicians to outreach workers.

The field coordinators perform a wide variety of duties within a particular service area. They are responsible for providing all project services to their assigned geographic area. Training of local outreach workers and particularly the local citizens is one major duty for the field coordinator. Similarly, dissemination of all types of information (pamphlets, posters, articles, advice, etc), is also a constant activity. The other major duty they perform is coordination of all clinics in their assigned area and keeping track of all patients from these clinics. On one reservation, Navajo, translation of materials into the tribal language has been important, while on all reservations a sensitivity to cultural differences has also been important.

The consultant dysmorphologists* have been indispensable. In addition to providing the key element of the entire project, the diagnosis of children, the dysmorphologists have provided the major direction in clinical knowledge. All initial training of clinicians was done by the dysmorphologists. The F.A.S. Project staff apprenticed themselves to the dysmorphologists in these sessions and eventually began to assume most of the responsibility for the training of other target groups. In addition to the clinical information, epidemiological, social, and counseling information has been added to the training when it is appropriate. Different levels and types of training are used for different groups, but the initial core of information was established by the dysmorphologists. The treatment plan for each child is also very important, and the dysmorphologist, with minimal input from others, is ultimately responsible for the plan.

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*The term dysmorphologist is used to describe pediatricians who specialize in birth defects and anomalies.

SERVICE AREA

The Fetal Alcohol Syndrome Project is being carried out among the American Indian population in New Mexico, Southern Colorado, Southern Utah and Northern Arizona. This is the geographic area covered by the Albuquerque and Navajo administrative areas of IHS. Indian groups served include the Navajo, Apache, 19 Pueblo Tribes, and Utes. The total number of reservations served is 26. The total number of Indians in the service area in 1980 was approximately 200,000. The land area served is vast and transportation and logistics are major considerations. Most travel is done by car, but the tight schedule of the dysmorphologists requires a charter plane for their outlying activities to prevent excessive hours in the car.

In the service area there are fourteen service units which encompass eleven hospitals and ten full time clinics. Each of these installations has served as a contact point for the project.

FAS CLINICS AS DEVELOPMENTAL CLINICS

Referral to the services of the project have come from a variety of sources within Indian communities, but are generally made through local IHS service providers at individual service units as described earlier. Whenever clinics are held they are "Developmental Clinics" where the end result is a variety of diagnoses in addition to F.A.S. and alcohol related ones.

All clinics have been directed by a dysmorphologist, and in each a team approach is used. Project staff and local clinic personnel alike perform a variety of support duties, such as taking basic measurements (length, weight, head circumference, Denver Developmental test, brief medical and social history, pictures for files, etc). Approximately one hour is spent with each child. Several people work together in the initial screening and one, two or three staff people generally are present during the dysmorphologist's examination. The main focus of the clinic is obviously on the needs of the child; but an equally important part of each clinic is the training of local staff. Teaching the local clinicians some of the finer and more subtle points of the clinical evaluation and habilitation of F.A.S. cases has been a major factor in virtually every clinic. This has two benefits. First, it provides a higher degree of knowledge to participants. The FAS staff learns more about the local conditions and the patients from the local staff. Inversely the staff learns more about F.A.S. and other birth

defects and developmental disabilities.* Secondly, though, it further stimulates and cements the relationship or bond between the project staff and the local clinicians.

In the initial planning of the project, the clinics were not named. It was assumed that they were F.A.S. clinics, but this proved to be a poor name. It soon became obvious that premature, negative "labeling" was a factor if they were called Fetal Alcohol Syndrome clinics or even dysmorphology clinics. One F.A.S. staff member, in searching for a way to name the clinic in an accurate, yet sensitive way, began referring to them simply as developmental clinics. This name has proven to be useful and has been consistently used by project and local staff to describe all of our clinics. It has proven to be accurate, for in gaining entrance to and respect in local clinics and hospitals, a variety of patients have been seen. Using a dysmorphologist allows this broader service which is very beneficial to the local medical personnel. Regardless of the ultimate diagnosis (F.A.S. or other) any child needing further, special treatment or attention receives a treatment plan. Therefore they have truly become developmental clinics.

## RESULTS

One of the best ways to evaluate the success of a program is to examine the results it has produced. In the following material, statistics and other information which have resulted from the project are described.

### TRAINING

From the begining of training (January, 1980) to October 15, 1981, a total of 208 training sessions were held. In these sessions 9556 people were trained by the three staff members who do training and the two consultant dysmorphologists. The three focal levels are represented in Table 1. The data indicate that 10.3% of those trained were clinicians, 25.6% were outreach workers, and 64.1% were community persons. The average number of people trained per session is 45. 9.

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Table 1 about here

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*On quite a few occassions members of the Indian Children's Program clinical staff have also attended the F.A.S. clinics.

In addition to the formal training sessions, a great deal of exposure to F.A.S. information has been accomplished through posters and pamphlets which were designed by the program staff. Over 6,000 posters have been printed with approximately 4,000 distributed to date. Currently 47,000 pamphlets have been printed and 36,000 have been distributed. Films have also been important media for the program. In the past eight months, 40 copies of 4 different films on F.A.S. have been lent to interested parties. Over 80 different groups have borrowed the films for at least one and in most cases, multiple viewings.

Other materials designed by the program have been widely distributed. A bibliography on Fetal Alcohol Syndrome and related issues has been developed and updated three times and it now includes over 300 entries. In addition, a resource guide listing films, slides, posters, pamphlets and other materials for F.A.S. education has been printed and distributed. All of the materials have been distributed both locally and nationally.

In general the training sessions and educational materials have been ethusiastically received at various levels. Several hundred different requests have been filled in the past year alone.

CLINICS

From the first clinic in March, 1980, to October 15, 1981, 20 clinics were held* in fifteen different locations. The results of the clinics are presented in Table 2.

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Table 2 about here

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The average number of children seen per day is 9.8. Multiple clinics have been held in four locations. More clinics are scheduled at the time of this writing. In addition, a number of other children were seen briefly at these clinics for other reasons (i.e. siblings of suspected children) but are not recorded in table 2.

The breakdown of diagnoses is also presented in table 2. It indicates that 30.2% of all children seen in clinics were Fetal Alcohol Syndrome and 15.6% were a a milder degree of damage, Fetal Alcohol Effect.** Another 6.8% were "Suspicious"

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*Three other clinics were scheduled: two were cancelled due to severe weather and an inability to fly in the dysmorphologist, and one in Spring, 1980 failed to produce patients.

**Fetal Alcohol Effect (FAE) is a milder form of prenatal alcohol damage in which the child has most of the features of Fetal Alcohol Syndrome, yet the features are less consistent and less severe.

or had some evidence of pre-natal alcohol damage and the remaining 47.4% were diagnosed as normal or as having another type of birth defect or anomaly. Some of the other diagnoses which were made include: Down's Syndrome, Hypoparathyroidism, Fetal Hydantoin Syndrome, Noonan's Syndrome, etc. It should again be emphasized that other types of developmental problems were referred to the clinics purposely so that the dysmorphology services could be used. Some of these referrals were made for anomalies which are similar in appearance to F.A.S. (i.e. Blepharophimosis), but others were totally unrelated and were made simply because the service was needed (i.e. Cornelia De Lang Syndrome).

The clinics have been successful in a number of ways. First, they have provided needed diagnostic services for a number of children. Second, they have been well attended indicating the success of the referral system and the process of implementing it. Third, they have shown that 45.8% of the children referred are definately suffering from some degree of pre-natal alcohol damage. This also indicates a rather successful referral system. Finally, they seemed to have helped create and/or maintain an interest in a variety of developmental disabilities. The serving of an underserved area with a needed specialty has been very gratifying to all.

RESEARCH

The research results of the project are still not fully obvious. Many interesting items are emerging which are of great interest. The patterns of incidence and some of the individual cases will eventually be of great interest. At the present time, however, detail is still needed. The incidence findings show great variation. In some service units and/or reservations no Fetal Alcohol children have been found, while others seem to have severe problems. This may accurately reflect the situation, though. In general the pattern of F.A.S. distribution is following the pattern of drinking and alcohol related problems described in the social science/epidemiological literature on Indians and alcohol use. That is, tribes with loose, band level social organization have a high incidence of alcohol damage; those with strict, highly structured tribal organization have fewer drinking mothers and a lower incidence of fetal alcohol damage. In general the current overall incidence of F.A.S. among Southwestern Indians may be higher than that reported in the general United States. In the U.S. one out of every 750 babies born is believed to suffer from F.A.S. Some of the reservations covered in the project have a significantly higher incidence than the U.S. which would cancel out the effect of lower incidence reservations and therefore make the overall incidence slightly higher. More accurate figures will soon be forthcoming.

One research finding which is of major importance is the pattern of multiple F.A.S. children to one mother. Among the mothers who have produced any F.A.S. or F.A.E. children, 22.6% have produced more than one damaged child (average 2.36 per multiple producing mother). This is very unusual, for no documentation of this exists in the literature except for two cases of twins. Only one case of twins has been found in the multiples in our project. It therefore is important to calculate the incidence figures in two ways; one, the number of damaged babies produced per normal babies; two, the number of mothers producing alcohol damaged babies per population. This will provide more specific indicators or risk and better insight for prevention.

The reason for the production of multiple babies is complex, but it is generally due to ostracism. In many Southwestern tribes, alcoholic women are not tolerated and are ostracized from regular social interaction. The consequence is an almost total lack of control over their behavior. These women generally migrate to bordertowns where their only friends and associates are other alcoholics. There is little stigma or negative sanction leveled at mothers who produce multiples within a setting dominated by a totally alcoholic peer group.

To reinforce the above statement other data indicate that mothers who produce alcohol damaged children are indeed, high risk in the social sense. Indicators of this include: a high percentage of the F.A.S. children are in foster placement (see table 2), a high percentage of the mothers are deceased (21%), and most have extensive clinic records for alcohol-related problems such as accidents, trauma, alcohol withdrawal, etc.

## CONCLUSION

Described in this paper has been a comprehensive program designed to study and impact upon the problem of Fetal Alcohol Syndrome among Indians in the Southwestern U.S. Training and education, clinical diagnosis and treatment, research and prevention are all components of this project. Each part has been set up in a manner which compliments the other. Therefore, the design of this project allows for a variety of action regarding this problem.

Generally the project depends highly on interaction and cooperation with a variety of community and medical interests. The structure of the project defined here can be implemented elsewhere with success. It is very important, however, that the type of program defined here be interpreted innovatively, flexibly and humanis-

tically. In other words, this system is a guide which directs and focuses efforts. It can and should be varied from time to time to meet the needs of local health providers, communities, and other cooperating interests. Teamwork and collegiality are vital to this entire program and its success. The services of this project are easily offered to communities in a sensitive and non-threatening way. Generally, offering needed services to local areas is an entre which ultimately is mutually beneficial. These services, general developmental evaluation, dysmorphology and the sharing of new information, help build a relationship which spans the gap between the project and local concerns. It is unlikely that a program without the strong clinical and research portions would be nearly as effective.

Results from the program serve as evidence that the system works. A vast number of people have been trained. Many children have been appropriately referred and diagnosed. Finally the research effort has provided new, existing and accurate information which will aid in future understanding, intervention, and prevention.

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FIGURE 1: Goals of the Fetal
Alcohol Syndrome Project

A. Training in the recognition and prevention of F.A.S. and all prenatal alcohol damage. Target groups include:

1. Clinicians,
2. Outreach workers - Public Health Nurses, Alcohol Counselors, Headstart Teachers, Community Health Representatives, etc., and
3. Community groups - Tribal councils, Schools, Local units of government, etc.

B. Provide for the clinical diagnosis of developmentally disabled children who are suspected of having F.A.S. The purpose of this diagnosis is:

1. Determine the clinical manifestations of F.A.S. in Indian Children,
2. Provide a treatment plan which can be carried out to maximize each child's development,
3. To refer children to the Indian Children's Program or other resources for needed services, and
4. Prevention of further F.A.S. children.

C. Research to better define the nature of alcohol damage to unborn Indian babies. Specifically addressed are:

1. Incidence and prevalence,
2. Etiology (medical and social), and
3. Prevention strategies.

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FIGURE 2:
FETAL ALCOHOL SYNDROME PROJECT

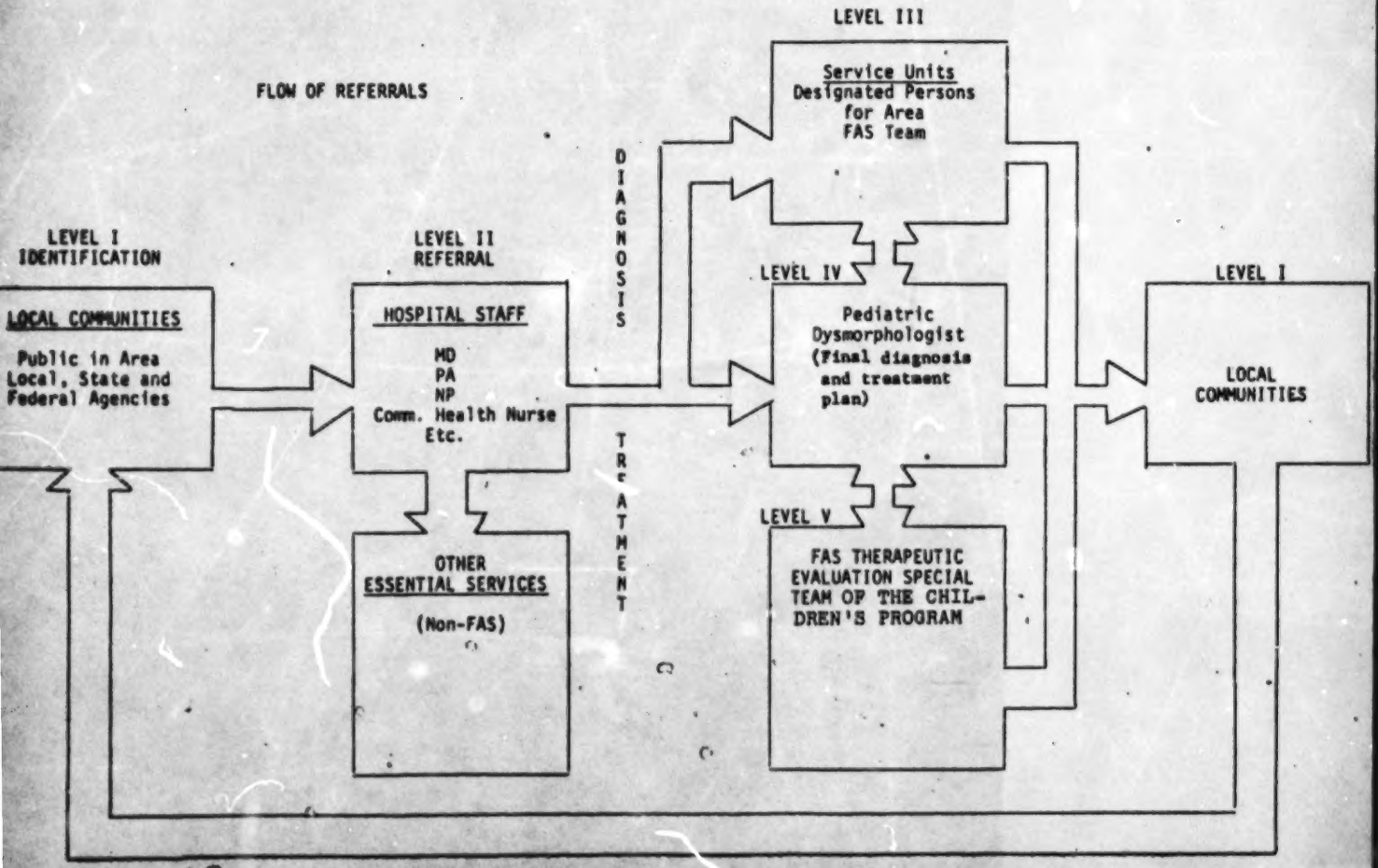

FIGURE 3:

INDIAN CHILDREN'S PROGRAM
MULTIDISCIPLINARY TEAM

Clinical Psychologists
Developmental Psychologist
Speech Therapists
Developmental Pediatrician
Occupational Therapists
Physical Therapists
Art Therapist
Vocational Rehabilitation Therapist
Educational Diagnosticians
Social Workers
Recreational Therapist
Child Psychiatrist

Table 1: People trained by the Fetal Alcohol Syndrome Project by Occupation, January, 1980 - October 15, 1981.

| | Number | % |
|---|---|---|
| Clinicians | 987 | 10.3 |
| Outreach Workers | 2450 | 25.6 |
| Community Persons | 6119 | 64.1 |
| Students (h.s. or below) | (5346) | (56.0) |
| Others | (773) | ( 8.1) |
| TOTAL | 9556 | 100 % |

Average (mean) per session = 45.9. Clinical and outreach worker sessions are generally smaller than the above average.

Table 2: Diagnosis of patients in Developmental clinics by sex and Foster placement, March, 1980 to October 15, 1981.

| | Total | % | Male | Female | Foster Placement | |
|---|---|---|---|---|---|---|
| FAS | 62 | 30.2 | 34 | 28 | 45 | (72%) |
| FAE | 32 | 15.6 | 23 | 9 | 23 | (74%) |
| SUSPICIOUS | 14 | 6.8 | 5 | 9 | 10 | (71%) |
| OTHER/NOT FAS | 97 | 47.4 | 59 | 38 | 56 | (57%) |
| TOTAL | 205 | 100% | 121 | 84 | 134 | 65% |

21 Clinic days, Average 9.76 patients per clinic